DOCUMENT RESUME

ED 351 842 EC 301 669

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TITLE	Disability and Family Policy.
INSTITUTION	Syracuse Univ., NY. Center on Human Policy.
SPONS AGENCY	National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE	92
CONTRACT	H133B00003-90; H133B80048
NOTE	11p.
PUB TYPE	Collected Works - Serials (022) -- Reports - Research/Technical (143)
JOURNAL CIT	Policy Bulletin; n2 Spr 1992
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	Agencies; *Cultural Differences; Cultural Influences; Cultural Pluralism; *Developmental Disabilities; Family Programs; Females; *Human Services; Policy Formation; Poverty; Public Policy; Services; Sex Bias; Sex Stereotypes; Social Bias; Social Class; *Social Integration; Sociocultural Patterns; State Standards
IDENTIFIERS	*Family Policy

ABSTRACT

This policy bulletin summarizes research findings about governmental and agency policies on community integration for people with developmental disabilities. It focuses on multicultural aspects of disability and family policy. The first section discusses implications of a multicultural perspective and identifies trends which take account of cultural influences on families receiving human services. The second section (by Rannveig Traustadottir) examines gender, disability, and family policy. It compares two rationales for family policy and family support services, suggesting that family support services may be based on outdated gender stereotypes which assume the consistent input of women's unpaid work in the home. Policymakers and service providers are urged to become aware of stereotypical assumptions underlying policies and practices. The third section (by Susan O'Connor) focuses on culture, disability and family policy. It notes the tendency of the dominant culture to see cultural differences as deficiencies. The fourth section is by Bonnie Shoultz and considers social class and disability. It identifies class categories, discusses the relationship of human services to family class positions, and considers the connections between poverty and disability. The final section offers recommendations for state level and agency level policymakers. (Contains 18 references.) (DB)

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ED351842

The Center On Human Policy

Research and Training Center on Community Integration, Center on Human Policy
Division of Special Education and Rehabilitation, School of Education, Syracuse University

Policy Bulletin No. 2
Spring 1992

Disability and Family Policy

ABOUT THIS BULLETIN

This is the second of a series of Policy Bulletins presenting information based on and summarizing research findings relevant to federal and state policy on community integration for people with developmental disabilities. These Policy Bulletins are sent, free of charge, to people involved in policy issues at the national and state levels. They are available, for a fee that covers the cost of copying and handling, to others who write for copies.

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This bulletin was edited by Bonnie Shoultz. Contributors include Rannveig Traustadottir and Susan O'Connor. Like everyone who considers gender, culture, and class, we are influenced by our own cultural, class, gender and racial identities, and our work reflects these influences. Bonnie Shoultz is a U.S. citizen of European ancestry, and has worked at various times with people and organizations in low income communities. Rannveig Traustadottir is an Icelandic citizen who has lived in this country for five years to study and conduct research on gender issues. Susan O'Connor is a U.S. citizen of European ancestry, and spent many years working in Morocco and with Palestinians on the West Bank.

(continued see page 10)

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A Multicultural Perspective

Demographic trends are rapidly changing the character of our nation and affecting all areas of human services. We have become more culturally, ethnically, and racially diverse than at any other time in our history. Human service workers, administrators and policy makers need new knowledge and skills to develop better relationships with the families who seek out or are thrust into the present service system.

The term multiculturalism has gained wide recognition recently and is interpreted in a variety of ways (Banks & McGee Banks, 1989). Multiculturalism is often understood as simply the study of a variety of cultures and as an exposition of their different characteristics and traits. However, many authors believe that taking a multicultural perspective means going beyond this focus alone and looking at other social forces that shape all of our lives (Gollnick & Chinn, 1990; Goodenough, 1987). In this view, multiculturalism includes the study of the effects of race, culture, class, gender and disability, though the latter is just gaining recognition as an area that should also be viewed through a multiculturalism lens.

A multicultural perspective provides a way of understanding ourselves, encouraging us to look at how our own values and perspectives affect our view of the world. It acknowledges the existence of a dominant culture, characterized by what we will call white, middle-class assumptions and behaviors, and encourages awareness of how different groups of people are affected by that culture's assumptions. Within human services, differences of race, culture, class and gender all affect how families are served, how human service professionals and other workers interact with individual family members, and how decisions are made about family matters.

The past decade has seen a dramatic shift in public policy regarding families of children with developmental disabilities. With that shift, family support services have emerged as an important component of the community service system. Other service components are now seen as having effects on family

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relationships that should be considered rather than ignored.

Today, the insights, concerns, and needs of families are increasingly acknowledged, and language such as "family-centered," "family-driven," and "family-determined" is promoted. In theory, these changes reflect a growing belief that family members have an important role to play in the services that affect the lives of all their members.

We can find a major example of the shift within developmental disability services by looking at how family support services have grown. This growth, which varies from state to state, is based on many factors:

*Policy makers began to heed the requests for support of families whose members with disabilities lived at home;

*Research on families began to emphasize family strengths rather than pathology and deficits, and defined families' needs for support;

*Family members of people with disabilities became active advocates for increased support to the home, delivered in a family-centered, flexible, nonintrusive manner;

*Policy makers came to believe that family support services would cost less than out-of-home placement;

*Family support services were viewed as preserving American family values--family support came to be viewed as the right and moral thing to do;

*Life within a family came to be viewed as better for the child with a disability than placement in a congregate setting.

Until fairly recently, developmental disability services focused on the person with the disability, not the family. At present, however, states are providing a wide range of family support services, and are making these available through a variety of means, ranging from direct cash subsidies to vouchers to agency-provided or arranged services (Taylor, Racino, Knoll, & Lutfiyya, 1987; Knoll et al., 1990). Within this new focus on families, however, many problems persist.

For example, even though policies and language are now more likely to be constructed with an awareness of their effect on families, many implicit assumptions about the nature and makeup of families continue to influence policy and practice. These assumptions have major implications for families, but have generally not taken into account the differences in gender, culture, race, and class among families.

The Center on Human Policy has studied services for people with developmental disabilities and their families from a number of perspectives. Between 1985 and 1989, through the Research and Training Center on Community Integration, we looked at what family members said they wanted and at what practitioners were providing (Taylor, Bogdan, & Racino, 1991). During those years, and especially after 1989, when our Community Study began, we have spent many hours with families who receive services. Throughout these years, we have seen that gender, race, culture, and class issues permeate policy and practice affecting families. This bulletin, which is based on data collected over these years, attempts to address some of the issues we have uncovered, and to make recommendations for policy makers.

Gender, Disability, and Family Policy

by Rannveig Traustadottir

While the growing interest in families of children and adults with disabilities should be welcomed, a review of the literature raises concerns due to the lack of critical examination of the role of gender within these families. The vast majority of the literature that has informed policy and practices directed toward families of children has been based on a view of "the family" as a unit.

The differences in activities and experiences of individual family members have for the most part been ignored. These studies routinely are characterized by gender insensitivity. That is, they ignore gender as a socially important variable, thereby overlooking the differences between mothers and fathers within the family. An examination of the literature reveals that there is an assumption, often unspoken, that mothers have the primary responsibility for caring for their children with disabilities. The literature also reflects the cultural stereotype of mothers as "natural" caregivers and assumes that women's primary orientation is toward family and motherhood. This both reflects and constructs how we see, understand, and interpret the lives of mothers of children with disabilities.

This article briefly outlines some of the assumptions about men and women at the basis of family support policies, and how stereotypical sex-role expectations influence the way service systems relate to mothers and fathers of children with disabilities. This article is an abbreviated version of an extended analysis of the role of gender in policy and practices directed toward families of children with disabilities (Traustadottir, 1988; 1991a; 1991b).

Rationales for Family Policy and Family Support Services

There are at least two major rationales behind family support policy that are based on assumptions that are problematic for women. The first rationale is economic, and asserts that family support saves money because it prevents costly out-of-home placements and may encourage families to take their children home from institutions and nursing homes. This rationale is supported by cost studies of services. When researchers compare the cost of residential placements and the cost of home care they find enormous savings when the care is provided within the family (Bradley, 1988; Governor's Planning Council on Developmental Disabilities, 1987). The second rationale is ideological: family support services are seen as supporting traditional American family values. One goal of family support services is to support the family as a unit, keeping families intact and helping families to take care of their own.

These two rationales are widely used to convince policy makers and service providers to fund and provide family support services, and have been widely accepted as two of the most powerful arguments in favor of family policy directed toward families of children with disabilities.

A critical examination of these two rationales raises serious concerns about the underlying assumptions about the roles of mothers of children with disabilities. The first concern is related to the cost savings of family supports. Why do family support services save money? The most obvious answer is that they save money because mothers provide most of the care needed by their children at no public cost.

The other concern relates to the idea of "traditional family values." Traditional family values bring to mind the culturally sanctified female role of caretaking and selfless giving. Traditional ideas and values about women's and men's roles within the family assign the responsibility for housework, child care and other caring work to women. Even today, women are expected to perform large amounts of unpaid work within the family. These traditional values also assume that women's primary orientation is toward family and motherhood, and that they have little commitment to paid employment. The reality today, however, is that the majority of women are trying to negotiate their caring role within the family with work outside the home.

An uncritical emphasis on these two rationales may lead to some serious dilemmas or conflicts. The questions must be raised: are we basing family support services on an outdated understanding of women's sex roles? and to what extent does current family policy assume and depend on the substantial and consistent input of women's unpaid work in the home?

Gender Stereotypes and Family Support Services

Cultural stereotypes of men and women also influence service practices and the way family support services are provided. Service providers have different views and expectations of mothers and fathers. The mother, who plays a central role in doing the caring work for her child with the disability, is typically also the main contact person for the service providers. Family support programs seem to have a certain idea about what mothers of children with disabilities "should be like," and these ideas reflect the cultural stereotype of the selfless giving mother who devotes her life to the welfare of her child and the family.

If the mother wants the services she cannot deviate much from what the professionals think she should be like. If she does, she risks being denied the services, and that can be devastating for a mother who desperately needs help. This creates a lot of pressure on the mother to conform to the professionals' ideas of a traditional mothering role.

The father is usually viewed differently by professionals working with the family. When a father is involved, his primary role is seen as being a supporter. This support role has at least three components. First, the father is expected to provide financial support and the

economic resources needed to keep the child at home. Second, the father is expected to be supportive of the mother's dedication and devotion to the child and her caring work around the child and the family. The third part of the father's support role relates to his participation in the caring work within the home and decision making around the child. The mother is generally the one who searches for services and investigates programs. If the father takes an active part in discussing the options and making decisions about the child's service needs he is seen as "very supportive and involved." The same is true if the father takes part in some of the caring work within the home.

Human service professionals talk differently about fathers and mothers. When talking about the fathers they tend to describe what the father "is like." For example, if the father is involved with the child, participates in the caring work, has contact with, and cooperates with the professionals they think he is exceptionally wonderful and praise him for being "so involved" with the child. But if the father is not involved with the child, and has no contact with the professionals, then that is what the father is like. They say, "We cannot force the father."

While service providers and professionals do not see themselves as having authority over fathers and are reluctant to put serious demands or pressure on fathers, they have less reluctance to pressure the mother. They demand a certain level of cooperation and performance from her, and try to influence what she does and how she does things. This raises some serious concerns about the way family support and other professional services influence and control the lives of mothers who have children with disabilities.

Conclusion

Most family policy and practice within the disability field reflect the cultural stereotype of mothers as the natural caregivers and assume that women's primary orientation is toward family and motherhood. Policy makers and service providers need to become aware of the stereotypical assumptions underlying policies and practices. In particular, we need to recognize gender as a critical issue when policy and practices are formulated, instead of coming to families with an approach that ignores the issue of gender and the difference between fathers and mothers, thereby perhaps reinforcing women's subordinate position in society.

Culture, Disability and Family Policy

by Susan O'Connor

Though the shift toward supporting families has benefitted many, the service system's views of what a family should be are strongly influenced by middle class, European-American values.

While there are many factors that affect the lives of individual families having a member with a disability, relatively little consideration has been given to families' cultural backgrounds. Culture has been defined in many ways (Banks & McGee Banks, 1989). One definition examines the heritage and traditions of social groups, and another views culture as a social group's design for surviving and adapting to the environment. In relation especially to the latter definition, culture can be viewed as having value, as defining and helping to maintain a group of people.

It is important to point out that culture is not exclusive to certain groups of people (African American, American Indian, Latino, Asian American) who are considered to be outside of the dominant culture. Culture is part of all of our lives, though it has often been viewed as something that other people have. We may attempt to understand the differences, and often what are seen as the peculiarities, of people outside the dominant European-American culture, without really seeing our own.

The service system reflects the dominant culture and therefore it is particularly important to recognize and try to understand the values, beliefs, and traditions of people from other cultures. Provision of services without this understanding can be damaging to families, because it lacks knowledge of what is supportive and what might be harmful to particular families. It is equally important to acknowledge the limited access to economic and political power that such groups often face (Cross et al., 1989).

Differences as Deficiencies

Typically, the differences that cultures outside of the dominant culture present have

been thought of as deficiencies, and people with certain cultural traits have been viewed as needing to be changed or corrected to fit into the mainstream. In the service system, the onus is placed on these particular people to change, to become assimiliated into the system as it exists. While this holds true for all families who are offered a service package or program and expected to fit their needs to what is offered, this is particularly evident for people from minority cultures (meaning groups having less power and fewer members) in this country. It is imperative that we begin to view cultural differences as strengths that can help us to better understand our system and what we are striving toward for families of children with disabilities. How might the system change to better meet the needs of all of the families it serves?

To provide appropriate supports for families of children with disabilties, we must understand the meaning of disability within their lives and the cultural contexts within which they live. A family's cultural background is something that strongly affects how they and the people around them relate with each other as well as their child with a disability.

Helpful or Harmful?

What is considered helpful in one culture might be considered an imposition in another. Where families of the dominant culture have struggled to gain more and better access to services, people of other cultures might be bewildered by the number of social workers and support people who come into their homes (Gartner, Lipsky & Turnbull, 1991). Labelling, so prevalent in mainstream U.S. culture, is often something alien to families of other cultures. Their children may take on the mantle of disability only when they are connected with school or services. When they are at home with their families or playing with neighbor children, they are just children, part of the group or family. For example, a Latino family has a child who has been labelled and placed in special education classes. Yet when the child is at home he is a regular member of his neighborhood. He knows his way around and plays with his peers.

As researchers observing families from minority cultures, we have seen that children with disabilities often have specific valued roles within the family, depending on their view of disability and the needs of the family. While this may be true in every culture, there are cultural differences in the roles that children are assigned. More research is needed in this area, which is just beginning to receive notice. Also, in some cultures, such as many Latino and Asian-American cultures, the family or extended family provide support that people in the dominant culture seek from services or friends.

Services, including those that have reputations as good, caring, and family centered, may ignore the cultural identities of individuals and families. This is most likely when a person works or lives in a facility operated by a service agency. For example, at the group home of an Arab-American man labelled mentally retarded, the staff were unaware of his Arab identity. To them, he was just another resident. When visiting family, and only then, he was Arab. This simple story is an illustration of how families and individuals may lose their ethnic and cultural identities when they become involved with the service system.

Conclusion

Today, cultural sensitivity is imperative in providing services to families. We must begin to look at our own and others' cultural orientations, and learn to appreciate the strengths of families who have learned to adapt to all that affects and shapes their daily lives and have, in their own unique ways, supported their members in the process.

Social Class and Disability
by Bonnie Shoultz

It is difficult to discuss social class in our society, for a number of reasons. One is the widely held belief that the U.S. is a classless society that offers equal opportunity to all. The belief carries with it a sense that class position has to do with individual characteristics and is earned, rather than the result of societal structures and forces over which individuals have little power.

Another reason discussions about social class are difficult is that most U.S. citizens consider themselves "middle class" (Rose, 1986), and the lines between classes are exceedingly blurred. While economists or sociologists may distinguish between groups of people based on income levels

or occupation type, these distinctions do not correlate readily to common ideas of social class. For example, the incomes of small business owners and skilled blue-collar workers may range from very low to quite high, and family income may range from low to high depending on whether there are one or two earners. Therefore, is it income, type of occupation, family makeup or how one was raised that determines class status? Futhermore, there is good evidence that the "middle class" as defined by income is shrinking. In fact, current projections indicate that downward mobility will be much more common in the future, that many sons and daughters of middle and working-class families will have lower incomes than their parents achieved.

Class Categories

In spite of these difficulties, I use the following class categories in this discussion: upper, middle, working, and poor. Use of these categories indicates recognition that U.S. society is characterized by different socioeconomic levels or classes, distinguishable based on their members' access to power, status, and money, as well as by how their members live and relate to the means of production. The upper class is made up of people and families who own and control corporations, banks, and other institutions that have power over goods and services. The middle and working classes are made up of families whose members sell their labor power or the products thereof. There is also a class of very poor people who find it difficult or impossible to sell their labor power. This class is disproportionately filled with people with disabilities, single mothers, elderly people, and people of color. These categories are used because they have meaning to most people and because they reflect the major distinctions having to do with occupational and income status in the U.S.

Human Services and Family Class Position

Human service organizations, including those serving people with disabilities, reflect middle-class expectations about how people should behave and how people should be treated, and their practices are based upon middle-class assumptions about the families and individuals they serve. For example, while studies have shown that middle, working class, and poor people typically hold the same basic values, differences have been found in child-rearing patterns, community participation, clothing, hairstyles, foods, speech patterns and pronunciation, body language, styles of homes, furnishings, numbers of people visible in the neighborhood, daily routines, music preferences, leisure-time preferences, amount of community involvement, and involvement with extended family (Kerbo, 1983).

How class-based differences are perceived by human service organizations can have major and lasting effects on people's lives. For example, a middle class human service worker, hearing speech patterns and pronunciations that he or she has learned to associate with a lack of education or ability, may suspect that the person speaking lacks the capacity to raise children, work, or fill other valued societal roles. At the very least, the middle-class worker must recognize and overcome his or her societally induced presumption that people who speak differently are inferior. At worst, the worker's unconscious prejudices can result in an unwarranted use of power over the person with a disability or his parents and a punitive withholding of support for the person or family member in social roles such as parent, worker, tenant, homeowner, or friend.

Human service organizations and their workers also tend to promote values that may conflict with the values of particular families. For example, agencies have traditionally emphasized both conformity to the rules of the organization and achievement of "independence," a state in which a person or family is self-reliant in carrying out the tasks involved in daily living. Many organizations today are promoting interdependence rather than independence and consumer control of services.

Any of these emphases, though, are likely to be perceived and practiced differently by people raised in middle class, working class, and poor families, and to create misunderstandings between human service workers and the families with whom they interact. Human service organizations, therefore, must be open to different ways of interpreting and responding to the values they promote, and must learn to recognize potential class biases in their expectations of people.

Poverty and Disability

Fiually, there is strong evidence that poverty causes and exacerbates disability. According to Krause and Stoddard (1989), the link between "activity limitation" (a Census bureau term that is broader than disability) and family income is clear. Over one fourth of the people in families whose annual income (in 1986 dollars) was under $10,000 have activity limitations. Many of these families have adult members with disabilities, who if unemployed are likely to have no other income than a small monthly benefit through Supplemental Security Income (SSI) or Social Security Disability Income (SSDI). Children in low-income households also have signficantly higher proportions of limitations than those in higher income families. Low-income families may have difficulty just obtaining food and shelter for their children, and rarely have the toys, clothing, medical care, and other resources that middle-income families view as necessities for their children with or without disabilities.

Also, because people belonging to racial minority groups are much more likely to be poor, there are many ways in which race, culture and class issues overlap. Some examples include labelling practices (poor and nonwhite children are more likely to be diagnosed as having certain disabilities) and the activation of human service agency control mechanisms (e.g., removal of children from the home, judgments about a family's willingness to cooperate or benefit from services, and others). Very often, especially when these other differences exist, a family's perspective about what is really needed by the family is overridden or reframed by agency workers. This can and does occur in the name of support, with little or no awareness by workers that their own middle-class standards are operating against families.

Conclusion

As with gender and culture, awareness of class issues should encourage human service workers and the system they represent to accept and understand the differences in families. Services offered to poor or working-class families, more than to middle-class families, may need to address the family's concerns about issues that have little to do with the disability of a family member. These concerns might include income support, medical care, assistance with housing, utility bills, or food, and other issues that affect the whole family and its ability to nurture a member with a disability. Services that are not flexible enough to address these needs are not likely to make positive differences in these families' lives, and may in fact cause harm to families.

IMPLICATIONS AND RECOMMENDATIONS

Developing a posture of respect, communication, and trust is a first step in approaching any family. Sometimes, being with and listening to family members can be more valuable to them than any type of material support. At the same time, care must be taken to preserve their privacy and ensure that their trust is warranted. Families have in common a need to be understood by the service world, but the circumstances of many families challenge us and them in different ways. We conclude with a number of recommendations for policy makers and workers whose decisions affect families:

RECOMMENDATIONS FOR STATE-LEVEL POLICY MAKERS

1. **Examine legislation, regulations, and practices that affect agencies' ability to provide flexible, family-centered services**. Too great an emphasis on accountability and measurable outcomes, for example, may produce agencies that feel they must approach families conservatively and from a stance in which they attempt to exert control over family decisions or patterns.

2. **Devise ways of ensuring that privacy is protected.** For example, a New Hampshire state family support program requires only very simple paperwork on family visits, even when serious personal issues have been discussed with a worker. After many families testified that too many workers were involved with their families, this state has also worked to reduce the number of workers interacting with a family.

3. **Identify regulations that pose problems for families and people with disabilities**. This may mean asking family members and workers from various cultural and class backgrounds to identify problematic regulations. For example,

does a regulation or practice assume that mothers will be available and willing to carry it out? Does a regulation or practice pressure people to conform to white, middle-class values or standards?

4. **Promote training and experiences that increase sensitivity to the variety of families and individuals agencies meet.** Such training could permit participants to expore their own backgrounds and their successes and difficulties in working with people who represent different backgrounds. Training of this nature must be nonjudgmental and must feel safe to participants.

5. **Develop individualized and flexible programs.** Consider cash support as well as vouchers, purchase of goods, or services. In Michigan, for example, direct-cash subsidies, with no strings attached, are very important to families to determine how best to meet their own needs. In several states, flexibility and individualization are enhanced through programs that emphasize family control over what and when services and good will be purchased or provided and what will be accomplished through informal family and community supports.

6. **Identify and support the strengths that exist in specific communities.** In most states, communities representing diverse cultural or income groups exist. Identify comunity strengths and work to develop local programs that build on community connections.

7. **Develop funding and incentives to enhance existing agencies or to start new agencies that meet the needs of diverse groups of families.** We do not advocate the development of separate services based on culture or class, but we do believe that states can use funding and other incentives to promote services that are more culturally sensitive.

RECOMMENDATIONS FOR AGENCY-LEVEL POLICY MAKERS

1. **Examine the beliefs, values, and assumptions held within the agency about men, women, poor people, and people of races and cultures other than those represented by the majority of agency employees.** What is the agency culture, and how well does it accommodate diversity? Solicit input on this question from workers, family members, and people with disabilities, and especially from those who are other than male, white, and middle class.

2. **Ask whether pressure is placed upon family members to conform to what is favored within the agency culture.** Are mothers, for example, listened to and supported in being the kind of people they want to be, or are they expected to conform to a certain image of what a mother should be? Are child-rearing practices that may reflect class or cultural differences understood and respected, or are subtle control mechanisms employed against these practices? Are families wanting services asked to accept beliefs (for example, about managing a child's behavior, purchase of goods, or even about ways of being assertive) that feel wrong or unnatural to them?

3. **Inform state policy makers of requirements that pose problems due to class, gender, or cultural insensitivity.** Advocate for culturally sensitive services and regulations, along with changes in monitoring practices. Propose development of state-level mechanisms to enhance multicultural awareness.

4. **Establish a climate which promotes respect, listening to and understanding of families.** Training and staff meeting experiences can be developed to establish this type of climate, as can an attitude toward workers that respects, understands, and supports them. Exploration of values and attitudes should be encouraged and should feel safe to all involved. At the same time, administrators and co-workers must not tolerate language or behavior that could be harmful or offensive to others. This may mean giving someone more information, intervening when offensive stories or jokes are told, setting up training for workers, or even issuing reprimands. We realize that this is a delicate balance to achieve.

FOR ALL POLICY MAKERS

1. **Examine your personal assumptions, especially in regard to how they affect policy and practice within the state or agency.** This should be a continuing process for anyone involved in making policy, whether that relates to regulations, personnel issues, direct contact with families, or other areas. Even basic assumptions having to do with the nature of integration, inclusion, participation, and interdependence may reflect gender, cultural, or class stereotypes and biases, and may result in coercion of

people with disabilities and their families to conform to something that is uncomfortable for them.

2. **Establish an advisory group to pull out these issues on a continuing basis.** Such an advisory group, including family members, people with disabilities, and staff members, could reflect the cultural, racial and class composition of the state or community and could be asked to identify areas for change.

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ABOUT THIS BULLETIN

(continued from page 1)

We are all women, and are all doctoral students at Syracuse University. We also believe that the responsibility for trying to create a more just and sensitive society should be a shared one. Therefore, while we do not represent people whose racial, cultural, and/or class backgrounds are different from our own, we try in our research to understand their perspectives.

We wish to express our appreciation to our informants and the many other people who have contributed to our thinking about how gender, culture, and class issues play out in disability and family policy. We would especially like to thank Steve Taylor, Bob Bogdan, Zana Lutfiyya, Julie Ann Racino, Pam Walker, and the other members of the research team at the Center on Human Policy. We would also like to thank Rachael Zubal for preparing the bulletin for publication.

This bulletin was prepared by the Research and Training Center on Community Integration, Center on Human Policy, Division of Special Education and Rehabilitation, Syracuse University, with support from the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research, through Cooperative Agreement H133B00003-90 and Contract Number H133B80048. No endorsement by the U.S. Department of Education of the opinions expressed herein should be inferred.

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This bulletin was produced by:

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